POSITION PAPER ON

SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS (SRHR) OF PEOPLE WITH DISABILITIES IN NEPAL

JULY 2020

BYAN Blind Youth Association Nepal

Visible Impact

This position paper has been jointly produced by Visible Impact and Blind Youth Association Nepal through their joint financial and technical support.

Visible Impact (Visim) is a young women-led organization that aims to bring visible impact on the lives of every woman, every girl, and every youth by unleashing the social and economic leadership of girls, women, and youth through beneficiary-partnered innovative interventions. Blind Youth Association Nepal (BYAN) is a national disabled peoples organisaton, established by blind and partially sighted youth with the vision of persons with disabilities enjoying dignified life in a inclusive society. As a right based organisation BYAN advocates to promote the rights of people with disabilities through capacity building, awareness, advocacy and participation and inclusion.

This paper has been produced through literature review, consultation with people with disabilities and their parents, and validation workshop with diverse stakeholders working with and for SRHR and/or people with disabilities.

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SRHR of people with disabilities is not a new issue in the development sector, yet it has not been able to gain significant momentum. We believe that this document can be an important milestone towards ensuring SRHR for people with disabilities through knowledge management and setting basis for advocacy. We expect that this position paper will serve as a basis to guide the subsequent advocacy efforts to enhance the SRHR experience of all types of persons with disabilities.

Finally, we appreciate everyone who directly or indirectly contributed in the preparation of this report. We hope that this paper will make difference to make sexual and reproductive health and rights accessible to the Nepalese disability population.

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Abbreviations

AIDS:	Acquired Immune Deficiency Syndrome
BPS:	Blind and Partially Sighted
BYAN:	Blind Youth Association Nepal
CDB:	Curriculum Development Board
CRC:	Convention relating to the Child
CSE:	Comprehensive Sexuality Education
CSO:	Civil Society Organisation
CEDAW:	Convention on the Elimination of All forms of Discrimination Against Women
DPOs:	Disabled Peoples' Organisations
FP:	Family Planning
HIV:	Human Immune Deficiency Virus
HMIS:	Health Management Information System
ICPD:	International Conference on Population and Development
INGO:	International Non-Governmental Organisation
MoEST:	Ministry of Education, Science and Technology
MoHP:	Ministry of Health and Population
NDWA:	Nepal Disabled Women Association
NGO:	Non-Governmental Organisation
NPC:	National Planning Commission
PoA:	Programme of Action
RM:	Rural Municipality
SDG:	Sustainable Development Goals
SRH:	Sexual and Reproductive Health
SRHR:	Sexual and Reproductive Health Right
SRR:	Sexual and Reproductive Right
STIs:	Sexually Transmitted Infections
UN:	United Nations
UNCRPD:	UN Convention on the Rights of Persons with Disabilities
UPR:	Universal Periodic Review
Visim:	Visible Impact
WHO:	World Health Organisation

Executive Summary

This position paper has been prepared through the joint effort of Visible Impact (Visim) and Blind Youth Association Nepal (BYAN). The purpose of this position paper is to create a dialogue amongst the policy makers, government agencies, Disabled Peoples' Organisations (DPOs), service providers in the area of SRHR and FP, development community so that reasonable actions are taken at all levels in order to address needs and issues faced by people with disabilities.

This paper is heavily documented based on desk review. A consultation with people with disabilities and their parents was conducted, and the cases highlighted in the story are derived mostly from it. A validation webinar was conducted represented by more than 50 activists, service providers, young people with disabilities, CSOs led by and/or representing people with disabilities and SRHR issues.

This assignment involved review of around 12 existing international and national documents relating to the conventions, constitution, laws, acts, policies, programmes, plans, guidelines. This document basically follows the gap between the international commitments that Nepal has made as a State party and the domestic legislative and program provisions. This position paper is also derived from review of literature, felt need and issues of people with disabilities, and the existing gap on the actual realisation of SRH services. It basically highlights the gap between 'what it should be' and 'what it is at the moment'.

The review revealed that despite large number of disability population of 514,000 in Nepal according to the census 2011, the SRH needs and issues of people with disabilities are often overlooked or neglected.

The review revealed that despite large number of disability population of 514,000 in Nepal according to the census 2011, the SRH needs and issues of people with disabilities are often overlooked or neglected. Worse, many people with disabilities are marginalized; they are deprived of freedom, and their human rights are violated. Historically, as part of this pattern, people with disabilities have been denied information on SRH and FP, accessibility issues are yet to be considered and there is a real gap to work on these issues by adopting a collaborative approach. In the context where society and family still consider that people with disabilities are not the beneficiary group of SRH, this paper is based on

the fact that people with disabilities are sexually active and have similar SRH needs to that of other people, and are further exposed to the risk of HIV, STIs and abuse.

The study also found out that Nepal has made many international commitments by ratifying different conventions and declarations. The Constitution of Nepal gives a broader scope to deal with the SRHR and FP needs of the people with disabilities. Similarly, the UNCRPD has been found to be progressive in provisioning SRHR and FP needs of the disability population whereas other tools such as SDG, ICPD, CEDAW were found to be little explicit or not explicit at all. Even the specific law enacted to protect and promote the rights of people with disabilities i.e. Act relating to the Rights of Person with Disability, 2017, has restricted provision with respect to the needs and issues faced by the disability population. The Safe Motherhood and Reproductive Health and Rights Act, 2018 also deviates from the SRH rights' perspective. The Disability Inclusive Health Guidelines, 2019 prepared by the Ministry of Health and Population is the most progressive document on the part of government till date. As a guideline, this document lays out strong foundation to address issues faced by the disability population. However, as guidelines may not be legally binding, they may not always be strictly followed, which in itself is a limitation. After all, accessibility remains as a major bottleneck for people with disabilities. Ensuring accessibility needs more understanding and commitment that goes far beyond than the resources alone.

The Disability Inclusive Health Guidelines, 2019 prepared by the Ministry of Health and Population is the most progressive document on the part of government till date. As a guideline, this document lays out strong foundation to address issues faced by the disability population.

Finally, some action points have been drawn at the end of this paper. These include working in partnership with the DPOs, reviewing existing laws, policies and programs from disability lenses, increasing access to SRH education, ensuring accessibility corresponding to the different nature of disability, promoting research connecting disability and SRH, and adopting a multi-tool (all human rights instruments instead of just focusing on CRPD) and multi-stakeholder (diverse development actors) approach for the full and effective inclusion of SRH issues and needs of people with disability at large.

1. Purpose of this position paper

While the SRH needs and services for the people with disabilities are generally unserved, this position paper intends to make a contribution to ongoing discussions on this issue among the Nepalese Government agencies, donor agencies, International NGOs, NGOs and Disabled People's Organisations, service providers, other civil society organisations and media. Organisations involved in producing this paper believe that human rights should be respected when planning and implementing SRH policies and programs, and thus not leaving people with disabilities behind. Policymakers should design policies and interventions based on evidence and not on political, class or any other biased viewpoints. Studies have considerable evidence regarding how SRHR needs of people with disabilities have not been reached out to or addressed[1] SRHR intervention packages are like unchartered water in terms of certain disability group i.e. people with intellectual disabilities, autism spectrum disorder etc. This needs further discourse, definition, development, and planning.

2. Methodology

This assignment mainly involved three methodologies i.e. Desk study, consultation and validation. The desk study involved the study of existing national and international laws, policies, programmes, plans, guidelines and other publications relevant to SRHR and Family Planning. Consultation was conducted among young people with disabilities,their parents and members of various DPO's.

For the final validation of this paper, a wider consultation was organised among the key national level DPOs/umbrellas/ federations involving more than 50 representatives from DPOs, service providers, activists and other CSOs working on the issue of people with disabilities and/or SRHR. Inclusive of team of BYAN and Visible Impact, the validation workshop was participated by the National Federation of the Disabled Nepal (NFDN), National Federation of the Deaf Nepal (NDFN), Parent Federation of Persons with Intellectual Disabilities (PFPID), Autism CareNepal Society (ACNS), Nepal Disabled Women Assocaition (NDWA), National Association of Hard of Hearing and Deafened (SHRUTI), Independent Living Centre of People with Disabilities (ICL) and National Association of Physical Disability (NAPD). These are the leading organisations representing different disability groups in Nepal. Inputs received from the national level validation workshop were adjusted accordingly to shape this document to its final stage.

3. People with Disabilities; Sexuality and SRHR Definition

3.1 Definition of disability:

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), defines Persons with Disabilities as "those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others". The Act Relating to the Rights of Persons with Disabilities, 2017 of Nepal has also defined persons with disabilities on similar grounds to CRPD.[2]

3.2 Classification of Disability

The Act relating to the Rights of Persons with Disability 2017 of Nepal has classified disability as follows:[3]

(A) According to the problems in the organs of the body and physical system, and nature of difficulty, disability has been classified into the following:

1. **Physical Disability:** Physical disability is the problem that arises in the operation of physical organ, its use and movement in a person due to the results of the problems in nerves, muscles and structure and operation of bones and joints. For example: cerebral palsy (polio), absence of a body part, effect of leprosy, muscular dystrophy, permanent problem related to joints and backbone, club feet, rickets, weakness due to the problem related to bones etc. are

physical disability. Person reached to the age of 16 however has very less height to that of average height corresponding to that age also fall into this category.

2. **Disability related to vision:** A person not having knowledge about an object's figure, shape, form, and colour due to following problem.

(a) **Blindness:** Cannot distinguish the fingers of hand by both eyes at a distance of 10 feet despite treatment inclusive of medication, surgery and use of spectacle or lens or cannot read the letters contained in the first line of Snellen chart (3/60).

(b) **Low Vision:** Cannot distinguish the fingers of hand by both eyes at a distance of 20 feet despite treatment inclusive of medication, surgery and use of spectacle or lens or cannot read the letters contained in the first line of Snellen chart (6/18).

(c) **Total Blind:** A person who cannot totally distinguish light and dark.

3. **Disability related to hearing:** Not being able to distinguish voice, place of rising and following tone, and amount and quality of voice due to structure of hearing organs. It is of following two types:

(a) **Deaf:** An individual who cannot hear sound above 80 decibels or who has to use sign language for communication.

(b) **Hard of Hearing:** An individual who needs hearing aid to listen who can hear sound between 65 decibels to 80 decibels.

4. **Deafblind:** A person having both hearing and vision disability or having disability with joint interaction of two sensory organs.

Father of a person with intellectual disability, Udaypur

"I am a father of 20 years old boy with disability. I can understand that he has same needs as me. I see changes within him and his needs and desires. But poor me, I cannot do anything for him apart from just keeping him at home. I urge government to work with DPOs to design SRH programs focused on such people."

5. **Disability related to voice and speech:** A condition due to functional limitation in the organs related to voice and speech resulting into difficulty in rise and fall of voice when speaking, unclear speech, repetition of words or letter is regarded as a disability related to voice and speech.

6. **Mental or psychosocial disability:** Due to the problems and awareness arising in the mind and mental parts that result into inability to behave in accordance with age and situation to perform intellectual functions such as orientation, alertness, memory, language, calculation is regarded as mental or psychosocial disability.

7. **Intellectual disability:** A condition where a person is having difficulty in carrying out activities relative to his/her age or environment due to the not having intellectual development is regarded as intellectual disability. (For example, Down syndrome).

8. **Disability Related to Genetic Bleeding (Hemophilia):** A person with physical condition where there is a problem of blood clotting due to factor disorder in the blood due to genetic effect.

9. **Disability related to Autism:** A Person having problem in nerve or tissue by birth and its function and development. (a person who has difficulty to communicate, to understand and use social rules, not being able to perform normal behaviour in accordance with his/her age, shows abnormal reaction, keep on repeating the same action, cannot socialize with others or show extreme reaction)

10. **Multiple disability:** The same person having two or more than two types of disabilities as mentioned. (For example, Cerebral Palsy)

ICPD also mentioned that the concept of reproductive rights "rests on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of reproductive and sexual health.

(B) Classification of disability based on the seriousness of weakness:

(1) **Profound disability:** A person with the condition of having difficulty to perform daily activities even when taking assistance from other persons.

(2) **Severe disability:** A person requiring continuous support from other to perform daily activities and to involve in social activities.

(3) **Moderate disability:** A person with the condition to participate in daily activities and social activities, with or without taking others' support, if the physical facility is available and environmental barrier is removed, and opportunities of training and education is provided.

(4) **Mild disability:** A person with the condition where one can participate in regular daily activities and social activities by self if there is no social and environmental barrier.

3.3 Sexual and Reproductive Health (SRH)

SRH is a state of physical, emotional, mental and social wellbeing in relation to all aspects of sexuality and reproduction, not merely the absence of disease, dysfunction or infirmity. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this condition are the right of human to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant (ICPD, 1994).[4]

Furthermore, the ICPD also mentioned that the concept of reproductive rights rests on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of reproductive and sexual health. It also includes the right of all to make decisions concerning reproduction free of discrimination, coercion, and violence as expressed in human rights documents.

Inadequare levels of knowledge about human sexuality and inappropriate or poor quality reproductive health information and services, prevalence of high-risk sexual behaviour, discriminatory social practices, negative attitude and powerlessness on the part of women and girls to decide on their sexual and reproductive lives makes the situation worse.[5] Barriers against the persons with disabilities compunds the risk.

To achieve all the above, free from discrimination, coercion, exploitation and violence, more specifically, sexual and reproductive rights (SRR) are outlined by the UN Committee on Economic, Social and Cultural Rights General Comment No. 22 where it is noted to have availability, accessibility, acceptability and quality as the main elements of SRHR.[6]

4. Disability and SRHR situation in Nepal

4.1 Disability Population

According to the Population Census 2011, the population of people with disabilities is 1.94% (514,000). Of the total disability population, the physical disability accords top (36.3%) followed by the BPS (18.5%) and Deaf and Hard of Hearing (15.4%). The population of speech related, mental and psychosocial disability is 11.5%, 7.5% and 6.5% respectively. On the other hand, deafblind has the lowest population (1.8%) followed by intellectual disability (2.9%).[7]

4.2 People with Disabilities and SRHR

Traditionally, although premarital and extra marital sex have been discouraged in Nepal and most of the Asian societies[6], studies conducted in different geographical settings have shown that unmarried adolescents in Nepal are becoming more sexually active and are also increasingly vulnerable to STIs and HIV infection due to changing values, norms and independence.[8]

To be human is to be sexual. Just like all human beings, people with disability are sexual. Those with disabilities are, first and foremost, people: they have the same rights, feelings, sexual desires, needs and possibly family dreams as anybody else. A positive body image and healthy self-esteem helps in pursuing and celebrating a pleasurable and healthy sexual and family life. At the same time, it is necessary to know how to set boundaries and how to protect against sexually transmitted diseases, unwanted pregnancy and sexual violence. In other words: all people – both male and female – with or without disabilities have the same needs in terms of access to and information about

'sexual and reproductive health and rights (SRHR), so that they can celebrate satisfying sex and having a family if, when, and with whom they want. However, the SRHR needs of people with disabilities often remain unmet. A profound worldwide misconception exists, that suggests people with disabilities are either asexual or hypersexual.[9] It is frequently assumed that persons with disabilities are not sexually active and therefore do not need SRH and FP services, research has shown that these group of people are as sexually active as other persons.[1]

In the context and societies where the 'person's disability' is accounted as a problem, the social perspective promoted by WHO is of high importance whereby the person or their impairment is not viewed as 'the problem', but rather understand disability as a result of the barriers they face in society.[10] Therefore, the challenges are not necessarily due to having an impairment in itself, but rather reflect a lack of social attention, legal protection, accessibility, understanding and support. The ignorance and negative attitude of

A 22 year old Blind Female

"People rarely talk about sexual aspects in my family and surroundings. So, I also feel shy to discuss on sex, sexual and reproductive aspects. Materials developed in this area are not in audio and braille format, so it is dif(cult to understand the content. People also question me on how I manage my family if I get married that makes me feel that I am not a human being. Government should provide proper education and blind friendly services".

society and individuals, including health-care providers, raise most of these barriers – not the disabilities itself. In fact, existing services usually can be adapted easily to accommodate people with disabilities. Increasing awareness is the first and foremost step. Beyond that, much can be accomplished by involving people with disabilities in programme design and monitoring.[1] This is all about understanding and adopting the 'social model' of disability in SRHR.

SRH demand in Nepal is still underserved (45% of total demand 72%)[11] by the SRH and FP service providers. Disability along with gender and geographical differences multiplies the discrimination further. Moreover, studies suggest that people with disabilities are twice as likely to be on the receiving end of inadequately skilled healthcare providers at improper facilities, and are three times more likely to be denied health care and four times more likely to be treated badly by health care systems.[12] People with disabilities are three times more likely to become a victim of sexual, emotional and physical violence where people with mental and intellectual disabilities are the most vulnerable ones.[13] Between 40-60 per cent of young women with disabilities and 16-30 per cent of young men with disabilities experience sexual violence before the age of eighteen[1]. Women and girls with disabilities have up to three times more chances of forced sterilization[14] and exposed to the risk of HIV[15]. One of the studies in Nepal found that 55% of disabled women had faced sexual violence. Among the victims, 20% had been raped, 45% of disabled women had faced sexual harassment, and similarly 30% of disabled women had faced verbal harassment. 5% of disabled women had faced forced abortion.[16]

A study carried out by MSI[17] showed that 96.5% of the young people with disabilities are not aware of all modern FP methods, 94% have heard of safe abortion, while 39% are unaware of legal status of abortion. Of those who

SRH is a state of physical, emotional, mental and social wellbeing in relation to all aspects of sexuality and reproduction, not merely the absence of disease, dysfunction or infirmity.

responded knowing safe abortion methods, 94% and 58% had heard of medical and surgical abortion respectively. Around 80% respondents had one or more myth or misconception associated with FP and abortion. Only 28% ever consulted with the service providers. In addition, 54% considered their service centers were not friendly to their disability because of lack of infrastructure—for example, lack of wheelchair accessibility (57%), service providers' negative attitude or lack of understanding of their need (29%) and absence of sign language interpreter (12%). Around one-fifth described difficulty communicating with service providers due to shyness, inability to read or write and lack of sign language provider. The study carried out by NDWA[16] among the women with disabilities also illustrated similar findings where 45% of women with disabilities were found to have different reproductive health related problems, 40% of women with disabilities (inclusive of married ones) did not have any information about contraceptives, 53% of the married women had never used any contraceptives. The same study also found that 50% of pregnant women with disabilities did not receive any basic SRH services while 66% pregnant women with disabilities experienced complicated issues such as tumulus period of nausea, soiling feet, abdomen pain and weakness. Among those who delivered child, 55% occurred at home without proper medical supervision, and similar percentage expressed that they did not get care and medication after the delivery.

Another qualitative study carried out by Visible Impact Nepal showed that worldview towards disability is a major barrier to access family planning services. Majority of the participants responded with not being aware of the SRH needs with difficulty in accessing SRH services. Structural and attitudinal barriers serve as major bottleneck with unfriendly health facility structures.[18]

5. Policy Instruments

5.1 International Policy Instruments

5.1.1 UN Convention on the Rights of Persons with Disabilities (UNCRPD), 2006

It is the first international human rights treaty of the 21st century, which entered into force on 3 May 2008. The Convention is the most widely negotiated and adopted international human rights convention in history, therefore there is high level of support to this convention indicating the critical importance on the rights of persons with disabilities. The following articles of the convention have direct relevance to SRH, reproductive rights, and gender-based violence:[3]

- Article 9 calls for accessibility, including access to medical facilities and to information.
- Article 16 requires states parties to take measures to protect persons with disabilities from violence and abuse, including gender-based violence and abuse.
- Article 22 asserts the equal rights of persons with disabilities to privacy, including privacy of personal health information.
- Article 23 requires states to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood, and relationships, including in the areas of family planning, fertility, and family life.
- Article 25 requires that states ensure equal access to health services for persons with disabilities, with specific mention of SRH and population based public health programmes.

5.1.2 UNCRPD Committee Report, 2018 (Concluding observations)

The UNCRPD Committee has recommended the State party to develop measures to ensure comprehensive access to health services, particularly sexual and reproductive health services for persons with disabilities.[19]

5.1.3 Convention on Elemination of all forms of Discriminaiton Against Women (CEDAW)

Article 16 Clause (1) sub-clause (e) has guaranteed rights of couples to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.[20]

5.1.4 UNCEDAW Committee Report 2018

The UNCEDAW Committee report 2018 recommends Nepal to ensure universal access to sexual and reproductive health-care services, of the SDG (point 39), incorporate age-appropriate and gender sensitive comprehensive sexuality education curricula that includes SRHR, responsible sexual behaviour and measures to prevent early pregnancy and sexually transmitted infections, at all levels of education, and train teachers to deliver those curricula (39a), reinforce measures with allocating adequate resources to have access of women and girls on high quality and age appropriate SRH care (39c) and end discriminations by health workers against women with disabilities (39d).[21]

5.1.5 Universal Periodic Review (UPR), 2015

The Universal Periodic Review (UPR) was concerned about extremely high maternal mortality and morbidity and recommended prioritizing universal access to contraceptive methods, improving access to abortion services, and taking measures to combat uterine prolapse. The country team recommended ensuring access to quality sexual and reproductive health services for every woman and girl (point 78). It is also recommended to remove legal and practical barriers (physical infrastructure, widespread stigma, inadequate registration, limited resource allocation and lack of access to inclusive services, for persons with disabilities (point 86).[22]

5.1.6 International Conference on Population and Development Programme of Action (ICPD PoA)

Referring to the provision made in CEDAW as above, ICPD PoA (Paragraph 7.3) explicitly calls for governments at all levels to consider the needs and rights of persons with disabilities and to eliminate discrimination against persons with disabilities with regard to reproductive rights and household and family formation: Governments at all levels should consider the needs of persons with disabilities in terms of ethical and human rights dimensions. Governments should recognize needs relating to the reproductive health, including family planning and sexual health, HIV/AIDS, information, education and communication. (paragraph 6.13).[1]

During the ICPD+25 Nairobi Summit, Nepal committed to provision of essential health services of good quality to all, especially marginalized and vulnerable groups, to move closer to universal health.[23]

5.1.7 SDGs and Universal Access to SRHR

The 2030 agenda and Universal access to SRHR has the target 3.7 of Goal 3 of SDGs as: Ensure Universal access

to Sexual and reproductive Health including for family planning, information and education, and the integration of reproductive health into national strategies and programmes.[24]

5.2 National Policy Instruments

5.2.1 The Constitution of Nepal, 2072 (2015)

The Constitution of Nepal has ensured several rights of persons with disabilities under the fundamental rights. Right to Equality: Article 18. (3) has adopted notion of non-descrimination and equality by stating that "persons with disabilities, pregnancy, incapacitated and helpless including others shall be treated equally. Article 38 (1) ensures equal lineage right without gender based discrimination of women while sub-article 38(2) ensures right to safe motherhood and reproductive health of woman." And in clause (3) it reiterates 'No woman shall be subject to physical, mental, sexual, psychological or other form of violence or exploitation on grounds of religion, social, cultural tradition, practice or on any other grounds.[25]

While Rights to Social Justice: Article 42(1), talks about inclusion rights of persons with disabilites in State bodies based on the priciple of proportional inclusion, sub-article 3 of the same ensures to have equal access to public services and facilities of persons with disabilities. Sub-article 5 even ensures rights to get priotized oppurtunity with justice and due respect in education, health, employment, housing and social security by persons with disabilities.

5.2.2 Act Relating to Rights of Person with Disability, 2017

This is the most recent disability specific act at the national level. The section 19(2) has urged Government of Nepal to make make necessary provisions for the protection of health and the reproductive rights taking into account of the special situation of the women with disabilities while section 7(1) has provisions for free health services. Similarly, section (17) provisions rights to have information in accessible format whilesection (39) talks about

SRH is a state of physical, emotional, mental and social wellbeing in relation to all aspects of sexuality and reproduction, not merely the absence of disease, dysfunction or infirmity.

accessibility in the hospitals, provision of sign language interpreters for deaf and deafblind, captioner for hard of hearing.[3]

5.2.3 Public Health Act 2075

This act has adopted the principle of non-discrimination and therefore disability is assumed to be included in general terms. In particular, section 42(2) stresses on construction of disability friendly infrastructures.[26]

5.2.4 Safe Motherhood and Reproductive Health Act, 2075

The Section 8, miscellaneous, has stated to provide services like family planning, reproductive health, safe motherhood, safe abortion, emergency obstretic and neonatal care and reproductive health in disability friendly manner. This provision is not legally binding since there is no provision for offense and punishment as it appears under the miscellaneous part of the Act.[27]

5.2.5 National Health Policy, 2076

The National Health Policy, 2076 has 6 objectives and 25 policies. This policy is general-overall in its nature where there is no particular focus on SRHR aspects of disability population apart from making disability friendly infrastructures and mechanism at all levels in order to ensure access to health by persons with disabilities (sub-policy 6.23.3).[28]

5.2.6 Disability Management (Prevention, Treatment and Rehabilitation) Policy, Strategy and 10 Year Plan (2017-2026)

This is the strategic plan of the Ministry of Health and Population to realize the health rights of persons with disabilities.

Mother of Person with Autism Spectrum Disorder, Kathmandu.

"We try our best to train parents with information on adolescent issues and bodily changes. However, this has been a challenge as there are individual differences along with communication challenge in autism community. Menstrual hygiene, attraction towards opposite sex but inability to handle are issues for most of the family members and matter of frustration to autistic adults. Parents' biggest worry has always been "what will happen to our autistic children after our death".

This document has been prepared upon having thorough analysis of international and national context in disability area and appears to be one of the most promising document. This document has defined five objectives where the reproductive health falls under objective 1. Under the plan of action, it has outlined to make disability friendly maternity services available to women with disabilities in 5 years' time period, and also make all health facilities disability friendly. This document considers women with disabilities as recipients of reproductive health, however perspective on SRH is somehow lacking. Despite these provisions, the actual progress towards what was planned has not been possible to track due to unavailability of documentation.[29]

5.2.7 National Guidelines for Disability Inclusive Health Services, 2019

In 2019, Ministry of Health and Population has come up with guidelines in order to make all health services of the government inclusive from disability perspective. Prepared with thorough reference on the international and national policy reference and with emphasis on the social model of disability, this document is the most comprehensive and progressive document in the health sector with respect to inclusion perspective where there is a separate section on inclusive SRH. This guideline has incorporated activities related to i) inclusion of disability disaggregated indicators in HMIS, ii) availing SRH services for persons with disabilities in all health faclities and hospitals, iii) social audit of the inclusive health services etc. Despite several fantastic provisions, this document comes as a 'Guideline' which may be morally binding but not legally binding.[30]

5.2.8 National Family Planning, The Costed Implementation Plan 2015-2020

One of the strategic action areas of CIP is to 'address legal and socio-cultural barriers to access FP services for young people and other special groups.' Within this strategic action area, the plan highlights to update the National ASRH strategy & review its implementation. Advocate with Ministry of Education, Science and Technology (MoEST), Curriculum Development Board (CDB) and key stakeholders to incorporate Comprehensive Sexuality Education (CSE) components in curriculum for Grade 9-10. Besides, this document also plans to develop a national strategy on increasing access to voluntary FP services among disabled people and support its implementation ensuring multi-sectoral co-ordination and collaboration.

Under the budgetary section of 'Enabling Environment,' in point 2, the government had planned to manage NRs. 3,720,500 for this heading. Out of which NRs. 1,300,000 was allocated in 2015 and 2019. However, the real impact tthat this budget was able to bring has not been measured. It appears that the ethical understanding of 'Leave no one Behind' is not completely on board while determining SRH and FP needs of disability group.[31]

6. Call for Action:

All efforts to include people with disabilities meaningfully, address their needs, and concerns in health policy and programmes must confront multiple challenges. In WHO's saying "The SRHR of persons with disabilities is not an unique, complex or highly specialized issue. It is, however, an issue that needs more attention and greater creativity and it needs to take actions now"[1]

Based on the rationale defined above, we call for following actions in order to effectively address the SRHR needs of people with disabilities.

1) **Establish partnerships with DPOs:**
   Working for the issues of SRHR of people with disabilities is not the responsibility of DPOs alone, and all CSOs should consider disability as a cross cutting issue rather than an isolated issue. As such, all CSOs, regardless of being led by people with disabilities or not, should include people with disabilities centred approaches in their interventions. The best way to start acting on SRH issues for persons with disabilities is to establish collaboration with people with disabilities and their representative organizations.

   DPOs can often help establish link with activists at national, federal or local level. Speaking with people with disabilities activists or representatives of such organizations and bringing them together for discussions, dialogue can concert the efforts towards inclusive interventions designs.

   "Nothing about us without us" is a key principle among people with disabilities. People with disabilities must be more than just recipients of SRH programmes and resources. Policies and programmes at all levels are better

when organizations of people with disabilities take part in planning from the outset. For this to happen, government entities at all level should establish health committee or taskforce with the inclusion of people with disabilities or include people with disabilities in their existing Health or similar taskforce or Committee if formed already.

2) **Revisit existing policy instruments to make it people with disabilities friendly:** Existing SRHR related act, regulation, policies have to be revisited considering SRHR needs and issues from accessibility perspectives of people with disabilities. The existing policies that contradict with national or international guidelines must be amended immediately and where they are not accounted, SRH rights of people with disabilities must be explicitly mentioned.

3) **Conduct disability audit of interventions:** The SRH of people with disabilities is not a unique, complex, or highly specialized issue. However, it is an issue that requires fair attention and accommodation for which DPOs can provide the necessary insights and support. Once it is embedded into planning process, the wheel goes on its own. Looking at the current national health plans and budget, Eg: FP Costed Implementation Plan 2015-2020, there is only NPR 1.3 million provisioned in each of 2015 and 2019. Firstly, the plan does not have budget for each fiscal year and secondly, the allocated budget is far more less. Therefore, provision should be made to make 'disability' as one of the key areas to audit existing SRHR programs (Disability SRHR Audit). Having such audit better ensures the targeted plan and budget to disability population.

4) **Include disability in national reporting systems:** Government of Nepal has a proper reporting system from the ground to document the status on FP commodities distribution in a prescribed reporting template. Also, robust HMIS system is in place to measure the health service utilization. Currently this reporting format does not include disability category, and therefore the utilisation aspects of FP methods/commodities by people with disabilities is not known. We, therefore, call government to make adjustments to its reporting templates accommodating disability group alongside of a plan with definite target to reach out to.

5) **Devise provision on reporting of sexual abuse and exploitation:** Some cases on sexual abuse of people with disabilities in general and girls/women with disabilities in particular become apparent, while many more cases of sexual abuse go unreported. Accessible abuse reporting and effective punishment mechanism including trauma counselling must be established to deal with the abused cases, and to stop likelihood of such cases in the future.

6) **Earmark Disability Specific Programming:** Not all people with disabilities, particularly, people with intellectual disability, autism spectrum disorder, and deaf blind will benefit from inclusion in the SRH efforts designed to reach out to general community or even general disability population. Such group of people need targeted level of understanding and learning patterns in a slower pace presented in a straightforward format, which needs to be repeated and reinforced. As of now, Nepal as a State fully lacks the ideas, approaches and intervention in this area. Therefore, separate program must be designed to find out the existing SRH practices and actual SRH needs of such population and address accordingly. Each RM, Province and Federal Government has to set aside 'fixed amount of budget' earmarking to SRHR of people with disabilities.

7) **Increase access to SRH education and services for people with disabilities:** People with disabilities are usually not considered as recipients of CSE education, be it for in-school or out of school children. Low school enrolment, low attendance and drop out from school when reaching puberty, has deprived people with disabilities with CSE at school. Moreover, the existing health curriculum aimed at various levels of medical education should also include SRH in connection with disability.

Father of girl with intellectual disability, Kathmandu

"I am a father of 20 years old daughter. It has been a real challenge to educate my daughter to manage her bodily changes and other biological developments. She does not know on how to manage all of these and we also do not know how to educate her on different aspects of SRH. Meeting her sexual needs are very challenging to reach".

8) **Adopt Life-cycle approach in SRH:** Like everyone else, people with disabilities have SRH needs throughout their lives, and these needs change over a lifetime. Different age groups face different challenges. For example, adolescents go through puberty and require information about the changes in their bodies and emotions, and about the choices they face concerning sexual and reproductive health related behaviour. Adolescents with disabilities need to know all this information, but they also may need special preparation concerning sexual abuse and violence and the right to protection from it. On reaching the age for having a family, women and couples with disabilities, like everyone else, have the right to decide whether and when to have children and a right to sound, unbiased information on which to base these decisions. SRH issues and needs at the later stage may further vary. Therefore, government should train its health staff to get them prepared to understand disability, different nature of disability and SRH needs/concerns and be able to provide age specific SRH support and services. Such services should also include mental health and counselling particularly at times of perinatal depression and suicide, mental health and psychological consequences of gender-based violence, or HIV/AIDS, feelings of loss and guilt after miscarriage, stillbirth, or unsafe abortion.

9) **Accessibility:** Physical access to buildings and clinics as well as other indoor and outdoor facilities is crucial to people with disabilities. Physical accessibility alone does not meet the needs of all people with disabilities. Communication materials and FP methods must also be accessible. Many adaptations to increase access can be made at little or no additional cost. For example, a clinic or a community health post, check-up room can be moved from an upper floor to a ground floor room, allowing individuals with physical disabilities to attend. A foldable cot available in an examination

On reaching the age for having a family, women and couples with disabilities, like everyone else, have the right to decide whether and when to have children and a right to sound, unbiased information on which to base these decisions.

room, which can be set up quickly for patients who are unable to climb on to an examination table. Forms that are simpler and have larger print benefit everyone. FP methods are available and provided to people with disabilities with the same rights to confidentiality, self-determination, and respect that everyone deserves. Therefore, all information and services must be equipped with accessibility standards, and these for example includes provision of ramps, larger bathrooms with grab bars, lowered examination tables, easy to read versions and simple languages, sign language interpreters, tactile communication provision, captioning, materials in large prints, audio format and braille script including pictorial form for persons with intellectual disabilities and autism spectrum disorder. Websites of the health agencies and service providers providing SRH services should be accessible to people who are blind with required navigation system.

10) **Promote Research on SRHR:** Worldwide, relatively little research has been done about the SRH of people with disabilities. This includes both disability-specific studies and the inclusion of people with disabilities in larger, population-based studies. In Nepal, there has been very few small studies/surveys carried out with regards to disability and SRHR. However, the studies are not comprehensive in the area of disability and SRH needs. To develop a better evidence base, research on SRH of people with disabilities needs to be promoted and such research should include disaggregated data on disability category. Other SRH research or health surveys should also include indicators on people with disabilities. For this to happen, government should provide funding to carry out small, disability category wise researches/surveys or link with the funding agencies.

11) **Model SRHR and FP provision:** The discourse on disability-inclusive SRHR has been coming up, however the real picture is yet to realise in terms of how its looks, equipped and arranged. This is about equipping the infrastructures, facilities, services, human resources and actual items from the disability lenses. Therefore, government, in collaboration with the DPOs, should establish such model facilities one per Province so that these could be taken as as reference for the learners, development actors, policy makers and DPOs self for future replication and expansion of SRHR and FP services.

12) **Advocate for Disability Inclusive Health Guideline at all levels:** On the context where, the MoHP has prepared a comprehensive document by addressing health issues in general and SRH issues in particular, DPOs are required to intensify the lobby and advocacy work with the Federal,

Provincial and Local authorities to take the planned actions in practice. It is not known yet how far this guideline has gone for implementation. Therefore, the government needs to track progress made towards the guideline with the institutional participation of people with disabilities and their representative organisations.

13) **SRHR and Human Resource Development**: To address harmful attitudes and behaviours towards people with disabilities, health service providers at all levels of the system need to possess clear understanding on disability, disability and SRHR. Without trained human resource, the goal of SRH inclusion will always remain in the peripheral location. So, the government, in dialogue with people with disabilities and their representative organisation, should make a phase-wise training plan to its health professionals. SRH education program targeting people with disabilities have to be designed and delivered in the school for individual awareness. Such education also needs to be provided to the parents for their parenting role on sexuality and SRH issues.

14) **SDG and Agenda 2030:** The goal 3.8 is related to sexual and reporoductive health and ensuring universal access. However, looking at its indicators, it is not explicit to persons with disabilities. So, space for open dialogue and discussions has to be created by the National Planning Commission and Health Authorities of Nepal in order to include SRHR and FP isssues of disability population in its upcomming 15th National Development Plan for which NPC has already come up with the approach paper.

Supreme Court of Nepal, Directive Order on SRHR

"In a writ jointly led by Nepal Disabled Women Association and Forum for Women, Law and Justice, the Supreme Court of Nepal issued directive order on 28th July 2010 to the Government to organise special programs to guarantee reproductive health and rights for people with disabilities, to arrange disability friendly beds and infrastructures in the hospitals, include SRH in school curriculum and to provide health service in priority basis in all the health facilities".

15) **Involvement of UN Agencies, CSOs and Development Partners:** It is important for UN, CSOs and development partners to review their existing policy and program framework from the lenses of disability and SRHR. All parties together or on their individual/ group capacity, can also actually pressurise GoN for the formulation of disability inclusive SRHR policies and programs. Apart from advocacy, development partner have to join hands with DPOs as their program partner to effectively address the SRHR issues of disability population and to make sure not to leave anyone behild.

16) **Multistakeholder Intervention Approach:** Nepal is a State Party for a number of international conventions, protocals and has made many commitments. These for example are UNCRPD, CEDAW, CRC, ICPD, FP 2020. There is also UPR reflecting overall human right situation. All of these are followed by concluding recommendations by the theme specific committees of UN. Surfacing the reports submitted by the State party and recommendations by the UN Committees, it appears that disability issue is overlooked apart from the UNCRPD one that is a specic convention. Therefore, DPOs, in coordination with other CSOs should actively involve in CSO reporting process and ensure the inclusion of disability and SRHR issues in reporting.

17) **Emergency and Covid-19 Responsive Plan:** In emergency situation and pandemic such as Covid-19, people with disabilities are at a higher risk of getting infected (assistive device, functional limitation to maintain social distance, inaccessible information, use of assistant). Thus, proper attention has to be adopted while providing SRH services. In emergency situations (earthquake, landslide, flood, fire) and during lock down, the mobility of people with disabilities is restricted and home based SRH service becomes inevitable.

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